



## **Dangers of the digital fit**

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*Published in:*  
Big Data & Society

*DOI:*  
[10.1177/2053951717752964](https://doi.org/10.1177/2053951717752964)

*Publication date:*  
2018

*Document version*  
Publisher's PDF, also known as Version of record

*Document license:*  
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*Citation for published version (APA):*  
Wadmann, S., & Hoeyer, K. (2018). Dangers of the digital fit: Rethinking seamlessness and social sustainability in data-intensive healthcare. *Big Data & Society*, 5(1), 1-13. <https://doi.org/10.1177/2053951717752964>

# Dangers of the digital fit: Rethinking seamlessness and social sustainability in data-intensive healthcare

Big Data & Society  
January–June 2018: 1–13  
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sagepub.co.uk/journalsPermissions.nav  
DOI: 10.1177/2053951717752964  
journals.sagepub.com/home/bds

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## Abstract

For years, attempts at ensuring the social sustainability of digital solutions have focused on ensuring that they are perceived as helpful and easy to use. A smooth and seamless work experience has been the goal to strive for. Based on document analysis and interviews with 15 stakeholders, we trace the setting up of a data infrastructure in Danish General Practice that had achieved just this goal – only to end in a scandal and subsequent loss of public support. The ease of data access made it possible for data to be extracted, exchanged and used by new actors and for new purposes – without those producing the data fully realizing the expansion of the infrastructure. We suggest that the case has wider relevance for a still more data-intensive healthcare sector and a growing data economy: when those who produce the data are not made aware of new uses of data, it makes it more difficult to resolve potential conflicts along the way. In the Danish case, conflicting views on legitimate data use led to the collapse of the infrastructure. Therefore, while seamlessness may be a solution to the old problem of a poor fit between user and technology, this celebrated virtue may also involve new problems relating to social instability. As digital solutions tend to be integrated still more seamlessly in still more of our activities, we need to develop political mechanisms to define and protect the rights and obligations of both data suppliers and users in order to ensure the long-term sustainability of digital infrastructures.

## Keywords

Denmark, digital fit, electronic medical record, infrastructure, seamlessness, sustainability

## Introduction

Do you have difficulties getting an erection? Are you worried about your looks? Or do you have problems with friends or finances? General practitioners [GPs] have reported such information to a national database for years without obtaining patients' consent. (Tynell and Fischer, 2014)<sup>1</sup>

In the late summer of 2014, Danish news media were full of reports like this. A public controversy developed around data extraction from medical records, akin to but fiercer than similar contestations in other countries, such as Australia, England and the Netherlands (Garrety et al., 2014; Smits, 2013; Sterckx et al., 2016; Vezyridis and Timmons, 2017). At the centre of the Danish controversy was a particular technology for the extraction, storage and exchange of health data,

viz. Dansk Almen Medicinsk Database, DAMD (the Danish General Practitioners Database). The controversy took the developers by surprise. DAMD was celebrated as one of the most important achievements in the history of quality improvement in Danish general practice; a 'visionary' and 'impressive development' (Boysen, 2011). However, following the intense media debate and the ensuing parliamentary discussion, the database was officially abolished in 2014 and data flows were suspended (Langhoff et al., 2016).

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DAMD was *damned*, as it were. This article revisits the DAMD case to explore what lessons it may hold for the social sustainability of digital infrastructures, also beyond general practice and the Danish borders.

In building a nationwide infrastructure enabling automatic data extraction from medical records with fast and tailored feedback on performance to GPs (Schroll et al., 2012), the developers of DAMD had mastered what had long been seen as a major challenge in digital development, namely to create a good fit between user and technology to allow for efficient and seamless work experiences (Ishii and Ulmer, 1997; Uschold and Gruninger, 2004; Yankelovich et al., 1988). With *seamless*, we not only mean that the technology was well-functioning, but also that it was embedded in a wider infrastructure that enabled the collection and exchange of a wealth of health data, without requiring much effort on the part of those providing the data. The ideal of a ‘digital fit’ has long guided digital developments (Hyysalo et al., 2016). It has even been worked into regulatory standards, such as the ISO Standard 9241-210:2010 outlining user experience as a precondition for the economic and social sustainability of digital solutions (International Organization for Standardization, 2015). However, the solution to the problems of yesterday often carries the germ to the problems of tomorrow. The achievement of the much desired ‘digital fit’, led to the emergence of new problems that eventually caused the shutdown of DAMD. It has previously been noted that incremental additions of new uses of data that are unrelated to clinical care may threaten the sustainability of digital infrastructures (Winthereik et al., 2007). Such a gradual layering of data uses has also been stated as a cause of the collapse in the case of DAMD: Langhoff et al. (2016) argue that the gradual inclusion of new data users with agendas clashing with existing ones led the data extraction to become politically contested and eventually break down. We take this argument a step further and suggest that the *mode* of expansion mattered and that it might in fact contain one of the key lessons having value beyond the specific case. We argue that the *seamlessness* strived for in the ‘digital fit’ undermined the social sustainability because it not merely enabled the expansion of data use, but did so without establishing the political checks and balances through which the legitimacy of new uses could be negotiated.

This point, we believe, is of wider relevance for the emerging global infrastructures of the data economy, even beyond healthcare. High-tech companies such as Google, FaceBook, Baidu and Alibaba deal in data, and their data markets thrive on seamless technology experiences (Creemers, 2016). On the one hand, these companies require enormous amounts of data to enable

the experience of seamlessness, because it is generated through tools of machine learning that are dependent of massive amounts of data. On the other hand, the companies depend on seamless data extraction to obtain these large amounts of data in the first place. In a self-fuelling process, seamlessness is both the end and the means of large parts of the current digitalized data markets. However, the seamless data generation typically comes with a lack of clarity regarding data use (Pasquale, 2015). As digital solutions become seamlessly integrated in still more of our activities, we therefore advocate a need for developing political mechanisms to define and protect the rights and obligations of both data suppliers and users, in order to ensure the sustainability of the emerging digital infrastructures and data markets.

### Infrastructuring, seamlessness and social sustainability

Bowker and Star (2000 [1999]) famously pointed out how infrastructures are often mistakenly considered technical, neutral constructs upon which other entities and activities run. Science and Technology Studies (STS) scholars argue instead that infrastructures should be understood not as a material conglomeration, but as forms of practice co-produced by human and non-human actors; hence, the notion of *infrastructuring* (Bowker et al., 2010). In the words of Star and Ruhleder (1996: 112), ‘infrastructure is something that emerges for people in practice, connected to activities and structure’. Infrastructures are built, rebuilt and function in certain ways, depending on which actors are involved in which ways, and how they are related (Danholt and Langstrup, 2012). Analytically, infrastructure therefore ‘appears only as a relational property, not as a thing stripped of use’ (Star and Ruhleder, 1996: 113). Whereas the design of information infrastructures tends to focus on the technical integration of system components (Ellingsen and Monteiro, 2003), it is equally important to recognize the contextual nature of medical information and the work it requires to make the information meaningful outside a particular context (Berg and Goorman, 1999). When referring to this dynamic process of creating, extracting, curating and storing data while simultaneously making them available for multiple purposes, we use the notion of *intensified data sourcing* (Hoeyer, 2016: 74). Today, automation has delegated much of this work to non-human actors operating on the basis of algorithms and other scripts (Stacey and Suchman, 2012). This may allow for seamless work experiences because the extraction, processing and storing of data require no immediate effort by the user. However, it also creates challenges of opacity, as it becomes

increasingly difficult for users to grasp how the data sourcing occurs unless specific effort is made to create transparency (Wyatt et al., 2016).

Discussions on visibility and invisibility in relation to infrastructure have a long history in STS. Star (1999) noted that ‘the normally invisible quality of working infrastructure becomes visible when it breaks’ suggesting that infrastructures are rarely noticed until they break down. Bowker et al. (2010) made a call for STS to do the work of what he called an ‘infrastructural inversion’: making visible the backstage and often under-valued work of infrastructuring and tracing the politics buried in technical encodings. Contrasting this approach, others have paid attention to the ways in which infrastructures are *made* visible as political symbols. Larkin (2013) emphasises what he calls ‘the grand spectacles’ of infrastructures: they often serve as highly visible symbols in political projects, even when they do little infrastructural work. The breakdown of DAMD made this infrastructure visible, while bringing an end to the infrastructural work – and we seek to understand how the seamless mode of data sourcing influenced the ability of the involved actors to ‘see’ the digital infrastructure they were part of and how the infrastructure was *made* visible by the actors as part of political projects.

The sustainability of digital infrastructures is not just a matter of technical integration; they embark on both technical and social resources to evolve and endure (Bowker et al., 2010). Often, the failure of digital systems to become infrastructures is depicted as unsuccessful attempts to link with other systems and adapt to changes in the environment (Edwards et al., 2009; Ellingsen and Monteiro, 2003). In the present case, the integration arguably became too successful (Langhoff et al., 2016) – but only because the expansion happened in a way that did not allow for political renegotiation of the interests at stake. It is this emphasis on conflicting views on legitimate data sourcing we mean to signify when referring to the *social* sustainability of infrastructures.

## Where and how: Exploring the DAMD infrastructure

To understand the historical rise and fall of DAMD, we tracked publicly available documents, and arranged them into a timeline. The documents include articles in national newspapers and professional journals (e.g., *Dagens Medicin*), an investigation of the case undertaken by a national healthcare authority (Statens Serum Institut, 2014), news updates, annual reports and a response to the before-mentioned investigation published by the Danish general practice quality unit (retrieved from: [www.dak-e.dk](http://www.dak-e.dk)). Because various

institutions and persons have differing interests in the presentation of the case, we made sure to include accounts that represented various viewpoints. Based on this overview, we identified actors who either worked with or sought to influence decisions regarding data sourcing in general practice.<sup>2</sup> We contacted them for semi-structured interviews to explore their perception of the DAMD case and how data mattered to them. Some of these actors played a central role in the development of the case, as they were involved in the development of the database, the administration of it or the political debate that ensued around it. Hence, the topic is sensitive to them. To protect the identity of the informants who requested this, we have had to withhold information on the exact position from which they spoke. Interviews were conducted with 15 informants. The interviews lasted between 65 and 180 minutes and were recorded, transcribed and coded based on open empirical questions including: How are purposes of data sourcing expressed, by whom and when? When does the infrastructure become visible for whom and in which ways? When do controversies arise, and what are they about? From the interviews it became clear that the notion of visibility of the infrastructure also mattered for how the case evolved. Hence, the visibility of the infrastructure became an empirical phenomenon worth exploring in its own right. We explored when it became visible and for whom, how the seamlessness of the infrastructure mattered in this respect, and in which ways the infrastructure was *made* visible. Before we move to the analysis of these processes, some information about the Danish context is necessary.

## Denmark: A data-intensive country

Denmark is a small and relatively wealthy welfare state in Northern Europe with 5.7 million inhabitants. While the Ministry of Health is ultimately responsible for the national healthcare system, five regional authorities are politically and administratively responsible for organizing the delivery of healthcare, including GP services. Healthcare services are paid mainly through taxes and are free at the point of delivery for all citizens. GPs are self-employed but receive most of their income from the regional healthcare authority with which they contract. These contracts are based on collective agreements. Citizens register with a GP, who will then refer them to the specialized healthcare services if necessary. There is an option of side-stepping the referral and increasing one’s free choice of provider in return for a co-payment, but only 1% of the population make use of this coverage option (Olejaz et al., 2012). In this way, GPs act as gatekeepers to the healthcare services as well as custodians of a longitudinal health record (cf. Vezyridis and Timmons, 2016).

In Denmark, the infrastructure of health data exchange goes to the core of the organization of the welfare services, and its contestation potentially affects everything that professionals and citizens do. Compared to many other countries, the Nordic countries are not only developed welfare states; they are also highly data intensive. We prefer the notion of *data-intensive* healthcare to the more fashionable notion of Big Data because it captures better the basic observation that multiple actors aim for more data, of a better quality and on more people without necessarily agreeing on what the data should be used for (Hoeyer, 2016). Since the 1980s, Denmark has also aimed for the position of being a digital frontrunner, and the country is repeatedly rated as one of the most digitalized countries in the world (Frost & Sullivan, 2017). In the area of healthcare, considerable state resources have been invested during the past four decades in the digitalization of medical records and in the enabling of data exchange across healthcare providers and different IT systems, e.g., through the production of standards. The tradition of centralized data registration of citizens, however, dates back to the beginning of the 20th-century. Residence registries have existed since 1924, before that the police kept residence records, and with the introduction of a centralized person register (CPR) in 1968 each citizen was assigned a personal identification number at birth or immigration (Willumsen, 1999). The CPR number is used in all interactions with the public services, including not only health services, but also social services, education, military service, income and taxation. All this data accumulation takes place without informed consent. Most private services use the traceability of the CPR system too, for example telecommunication, transport, banking and even gyms and grocery shopping bonus programmes use this number.

Taken together, these opportunities for tracking of individuals throughout life have given Denmark the reputation as ‘the epidemiologist’s dream’ (Frank, 2003). While such state-controlled data assemblage would be controversial in many other contexts, it is rarely questioned in Denmark. The seamless data exchanges make a number of everyday operations run very smoothly, and though some studies refer to a ‘crisis of trust’, surveys of citizen attitudes continue to report relatively high levels of trust in state institutions (Mandag Morgen, 2016). However, as the DAMD case rose to the national political agenda, it made visible the seamless data infrastructure in ways that made some health professionals and citizens publicly express distrust in the public administration of health data.

We seek to develop these points, as we now turn to the analysis. The analysis is divided into three parts. First, we describe the vision that the developers of DAMD pursued. Next, we demonstrate how the

purposes of data sourcing gradually accumulated over time, as more actors were included in the infrastructure. We use the term purposes to signal an *ambition* of data use; it does not necessarily imply actual use. As we will demonstrate in the analysis, the articulations of ambitions can have profound effects, even when the actual state of implementation is difficult to pinpoint. Last, we show how the efforts of the developers to enable seamless data flows also made it possible to overlook divergent views on legitimate data use, until they surfaced as outright conflict.

## A vision of data-driven quality improvement

DAMD was developed around 2005 by a small group of pioneering Danish GPs, who had led the way in digitalizing medical records and worked hard to introduce what they called ‘data-driven quality development’ in general practice. For the developers, the tools they were developing constituted part of making general practice a modern and future-oriented place of chronic care. One of the developers, whom we will name Erik,<sup>3</sup> was a GP himself. Recognizing what he saw as important virtues in general practice, he envisioned that GPs could lead the way in chronic care. ‘Our virtue is that we know the patients. [...] We also know the social conditions and so on’, he explained and continued: ‘so general practice is really well suited for chronic care’. What were missing, according to Erik, were feedback mechanisms that would offer GPs a better overview of their patient populations and some means to evaluate their own work in a structured way. He explained: ‘As a GP [...] you’d actually like to know how you’re doing’. But because the GPs lacked the tools to identify relevant patient populations, Erik noted, it was difficult to know how well the patients were being treated:

In general practice, it’s patient contact *full time*. [...] [GPs] have individual contacts, but not really an overview of the population. [...] You may have 20 really well-treated diabetics. But if you haven’t found the other 50, it might not look so good after all.

In the experience of Erik and his collaborators, shifting the perspective from the individual patient to the population made them realize that the most vulnerable patients in the greatest need of care were also those who did not show up for check-ups. Hence, to enable GPs to care better also for those patients who fail to appear they started to set up what they came to see as a system for ‘data-driven quality improvement’. DAMD was the result of this work, but more effort was required before it was in place.



### *Standardizing, centralizing and automating to enable seamless data flows*

A first effort included the standardization of information registration through the development of a Danish version of the International Classification of Primary Health Care (ICPC). This was published in 1992. By coding patient contacts in a uniform manner, Erik explained, he and a handful of colleagues were able to start ‘retrieving data from the electronic medical record’ and combine them with other data sources, e.g., from laboratories. The purpose was to improve the quality of care, and the means was a standardization that would allow comparisons between patients and patient populations. However, for the technology to fit into the busy work life of GPs, it needed to be easier to use. According to Erik, a pilot run in the late 1990s showed that GPs had to spend a whole day every third month to generate even very simple statistics for just one patient group. Erik remembered thinking: ‘it must be possible to do this in a more rational way’. He continued: ‘it made me realize that these data needed to be gathered automatically’. Thus, the developers strived to automate the mode of data sourcing. This agenda of automation has become a key feature of the grander data economy, creating a series of invisibilities (O’Neil, 2016). In the Danish case, the ambition was not to create invisibility per se, but to generate data ‘without disturbing the physician’ (Schroll, 2013: 3). The rationalization efforts included new actors in the infrastructure. Following a collective agreement between the general practitioners organization (PLO) and the regional authorities, a GP Quality Unit called Dansk Almenmedicinsk Kvalitetsenhed, DAK-E, was established during 2003–2006. Headed by some of the developers of DAMD, DAK-E was given a prominent role in the data infrastructure. With responsibility for the daily operation of DAMD, DAK-E undertook the data cleaning, developed the algorithms that allowed for the combination and presentation of data and delivered ‘readymade quality reports’ to the GPs, as Erik phrased it. In this way, the ‘articulation work’ necessary to keep the standardized processes on track was moved from individual GPs to the quality unit (cf. Strauss et al., 1997 [1985]). The effort to automate the data sourcing also brought a new material actor into the infrastructure: the software Sentinel Datafangst. *Sentinel* means lighthouse: it ‘brings light and shows the way forward in quality development’, DAK-E explained (DAK-E, 2013). The Danish notion of Datafangst can be translated into *Data Catch*. So it was called because the software made it possible to ‘catch’ data from the medical records, a developer explained. The ‘catch’, or the extraction we might say, entailed that the structured information in the

electronic medical records was automatically copied on a daily basis and the copy stored in DAMD. Hence, GPs could use the tool without bothering about the concrete data management and analysis. In sum, through efforts to standardize, centralize and automate the sourcing of data, the developers strived to achieve a seamless and efficient work experience, in order for the technology to fit into the busy work life of the GPs.

### *A helpful tool*

The result of all these efforts was a system that made use of data recorded as part of routine care and, for the first time ever, provided GPs with the option of easily having their patients shown as a population stratified according to registered diagnoses. Clinical indicators were provided for GPs to be able to check the treatment status of individual patients with certain registered diagnoses. These indicators also allowed for benchmarking against national averages, enabling GPs to identify their own weak spots. For patients with diabetes, clinical indicators would for example include blood sugar levels, blood pressure and prescribed medications. Moreover, visual cues were offered to make it easier for GPs to detect patients who might require clinical attention. For example, colour markings would draw attention to potential risks (e.g., increased excretion of protein through the kidneys, indicating kidney impairment) or provide swift identification of patients who had not attended an annual check-up within a given time frame. In addition, cross-tabulations made by DAK-E on the request of GPs allowed for easy identification of patients who were eligible for certain services (e.g., free influenza vaccination) or were treated with certain medications (e.g., medicines soon to lose subsidization). ‘In this way, you could run the clinic more efficiently and provide better treatment for the patients’, Erik stated. Not only the developers liked the system. It was also seen as helpful by GP-users, as it allowed them to keep better track of patients and provided information of relevance to treatment decisions (Lippert, 2014). Even people who later became fierce opponents of the system look back upon it as being helpful. In the words of one of the GPs who led the opposition against DAMD, it provided ‘a fantastic overview’ for GPs when treating patients with chronic diseases. A leader from a regional government even referred to the system as ‘about the best thing that has happened in the Danish healthcare services for years’.

At this point in the development, GPs envisaged data circulating in a closed loop. Developers and regional authorities agreed with this view and saw GPs as both the data producers and users. The purpose was

quality development understood as efforts to assist individual GPs (and patients) in making decisions about treatment practices. However, once the standards and means for easy data exchange were in place, stakeholders saw new opportunities. The purposes of data use that they added transformed the infrastructure; in the words of Langhoff et al. (2016), it fundamentally altered the ontology. The incremental addition of purposes of data use was seamless from the point of view of the GPs, in the sense that it did not require any extra work of them (cf. Berg and Goorman, 1999). They could continue their routines, while data began traveling further and acquire new functions.

### The seamless accumulation of purposes

From overviews serving the individual GP, data from DAMD also came to be used for decision-support in the encounter with patients. As collaborations developed between DAK-E and the scientific college of general practitioners in Denmark (Dansk Selskab for Almen Medicin, DSAM), the infrastructure expanded and DAMD also came to support the implementation of clinical guidelines. While this hardly challenged the purpose of enhancing the quality of clinical care, it opened up a process of adding new purposes and stakeholders to the infrastructure. Table 1 summarizes this

accumulation of purposes. The table is intended as a simplified illustration of the multitude of purposes and for some of the purposes, it is difficult to say whether they gave rise to actual data practices. In particular, it seems that the purposes of audit, healthcare management and national economic growth were merely articulated as policy ambitions. Nevertheless, these articulations had profound effects among these GPs, who disagreed with their legitimacy.

As data accumulated, researchers began to apply for access to DAMD data. From about 2010, Erik explained, enough data had been gathered for DAMD to constitute ‘a gold mine of information for research’ and over time about 80 projects made use of anonymized data from DAMD. The regional authorities who co-funded the activities also wanted to benefit. According to an administrative employee, who we will call Morten, the regional authorities felt that ‘for quite some years it had been limited what the Regions had gained from [financing the data collection]’ and that the Regions ‘had to create some value’. In 2010, the regional authorities initiated negotiations with the Danish GP organization about the collective agreement with an extensive ‘wish list’, the employee explained, and they succeeded in having most of their demands met. Consequently, it became mandatory for GPs to install Sentinel Datafangst, code patient contacts for eight specified conditions, let data from the medical records be copied to DAMD, and subsequently to clinical databases administered by the regional authorities. This allowed the authorities to pursue an ambition of cross-sector quality monitoring by linking data from general practice with data generated in the hospitals.

Moreover, the agreement required GPs to publish data from the medical record on a web portal, Sundhed.dk (Health.dk), where citizens can access their own health data online with a log-in, and other health professionals than the GP are allowed to view it when relevant for a given treatment. In this way, a new purpose of patient empowerment entered the infrastructure along with enhanced opportunities of cross-sector care. Whereas GPs had previously had the option of letting only selected data be copied to DAMD, Erik explained: ‘Now we had to send *all* the data to Sundhed.dk. It was in the agreement’. Therefore, a material reconfiguration was made that altered the data flow profoundly: Sentinel Data Catch was adapted so that *all data* except case notes were automatically copied from the medical record to DAMD. The transfer to Sundhed.dk also necessitated a translation of diagnostic codes because codes used in general practice were not fully compatible with the codes used on Sundhed.dk. In consequence, some patients were surprised to read diagnoses on the online portal that they had never heard from their

**Table 1.** Accumulation of purposes with data use.

From	Purposes
2006	Quality development in general practice (undertaken by GPs) <ul style="list-style-type: none"> <li>–Population overview</li> <li>–Benchmarking opportunity</li> <li>–Clinical decision support</li> <li>–Individualised risk profiling</li> <li>–Support for guideline implementation.</li> </ul>
2010	Resource for research <ul style="list-style-type: none"> <li>–Epidemiological studies.</li> </ul>
2010	Cross-sectorial quality monitoring (undertaken by health authorities)
2010	Patient empowerment <ul style="list-style-type: none"> <li>–Access provided for patients to read structured information from their own health records through a public web portal.</li> </ul>
2012	Management information for regional healthcare authorities <ul style="list-style-type: none"> <li>–Resource for audit.</li> </ul>
2012	Management and planning tool for health authorities <ul style="list-style-type: none"> <li>–Community level risk profiles</li> <li>–Support for development of disease management programmes</li> <li>–Resource for early warning research.</li> </ul>
2013	Motor of national economic growth

doctor. Not all translations were equally successful and even GPs were surprised by some of the algorithm-led translations; for instance some codes for mental strain were mistakenly translated into a diagnosis of pyromania. The subsequent reactions illustrate the increasing visibility of the new data flows for GPs.

While officially serving the goal of patient empowerment, it was also acknowledged that enhanced transparency for patients might enable a new form of control. An employee who had been involved in the set-up of the data extraction from DAMD to Sundhed.dk noted that the project was given the working title ‘the snitch’ because it was envisioned that ‘citizens would login and check whether doctors were cheating and inform [the authorities], if the doctors had billed services which patients hadn’t received’. In an interesting move, the system that was designed to allow individual doctors to identify the patients who did not comply with treatment plans was now inverted and seen as a tool that would allow patients to single out the doctors who might not adhere to billing guidelines. This ambition of monitoring doctors rather than patients was further expanded, when DAMD came to be seen as a resource for external performance monitoring. A leader in a regional healthcare administration explained: ‘you know, there are probably also some mavericks in general practice and one could imagine that there might be clinics that do a really poor job’. Another leader elaborated:

In my view, it should be a perfectly legitimate request from a customer – who pays a considerable sum to a provider to complete a task on behalf of tax-payers and patients – to want some insight into how the task is solved and which outcomes it generates.

In the view of these officials, the demand for data is legitimate because it is understood as a precondition for qualified administration of public resources. While they saw it as a legitimate purpose, they also stressed that it required agreement regarding the conditions for data use and collaboration between GP representatives and the regional healthcare authorities. According to Erik, however, he was contacted directly by a head of division in a region and asked for performance information on individual GPs:

Before the negotiations for the collective agreement [between the regional authorities and the GPs’ organization] in 2013, [the head of division], called me during my summer holidays and asked for data on which diagnoses were given to the patients who had received conversation therapy. Because he wanted to see if [the fee for] conversation therapy had been used for anything else [than what had been agreed].

For some officials, DAMD data was becoming a tool of accountability (cf. Winthereik et al., 2007). Other officials emphasized the possibility of using DAMD data for planning purposes, e.g., in the setting up of disease management programmes, for revealing patterns of demographic change and as early warning signs of epidemics. According to the informants we encountered, these analyses were never performed, and DAMD data was never forwarded to the regional authorities. DAK-E rejected the requests because they found them to be outside the existing agreements. Nevertheless, it is clear that once the set-up allowing for seamless data sourcing was in place, it inspired new uses and invited other data users, as has been the case across a range of sectors using new digital tools to reinvent the purposes of data accumulation (Madsen et al., 2016).

Along with the negotiations with regional authorities, ‘state pressure’ for access to DAMD data was also instituted, people working in DAK-E noted. They explained how representatives from the State Serum Institute (SSI) under the Ministry of Health came to visit in 2013 and requested a copy of all DAMD data. In 2012, SSI had been tasked with the collection and dissemination of all national data on population health, health service activity, economy and quality, in an effort to centralize the administration of health data. Despite the pressure, DAK-E opposed this request. An employee from DAK-E explained: ‘you know, the SSI wanted to use it for government consultancy – and government consultancy ... that is control’. At that time, prominent themes in the political debates were reform of payment models in the healthcare services inspired by British models of pay-for-performance, but also the idea that health data constituted an under-used resource, which, if used in the right way, could potentially stimulate economic growth (cf. Vezyridis and Timmons, 2017). Hence, political ambitions were voiced to turn Danish health data into a motor of national economic growth, by providing private companies with easier data access (Regeringen, 2013). According to DAK-E, all these agendas ‘created pressure’ and ‘made everybody nervous about how these data would be used’, as one of the informants noted. The informant’s notion of ‘everybody’ illustrates an emerging sense of data anxiety.

To sum up, as new actors became part of the infrastructural practices, DAMD data was put to new forms of use. Initially a tool for quality improvement, it also became articulated as a tool for research, patient empowerment, healthcare planning, efficiency gains and economic growth. These changes happened gradually and without individual GPs necessarily noticing the change. The seamless data experience was more or less unaffected by the new uses and the infrastructure remained largely invisible to the GPs and patients



providing the data. However, the expansion of the infrastructure involved a considerable potential for conflict. GP-users did not experience friction in their daily work, but this did not mean that the potential for conflict disappeared. Rather, conflict arose as GPs came to realize how much data was collected from the medical records and how many purposes data might serve. Whereas failure to enrol new actors in an infrastructure is often seen as a cause of instability (e.g., Modol and Chekanov, 2014), the situation here appears to be reversed: the sustainability was threatened by too much integration (Langhoff et al., 2016). This proposition we develop in the following as we unfold the controversy evolving around DAMD.

### From seamless efficiency to fierce contestation

An especially loud voice in what was to become a heated debate about DAMD came from a small fraction of GPs for whom the issue of data became a route to political engagement. They self-identified as an informal group of what they themselves called the ‘data-engaged GPs’ and coalesced around a network of GPs named SPRAL. SPRAL refers to *Selvstændige PRAktiserende Læger* which means Independent General Practitioners. For one of the data-engaged GPs who led the opposition against DAMD, the gradual expansion of purposes was a key source of concern. She explained: The idea was that DAMD would be ‘a tool to provide the physician with a better overview for the sake of improved patient treatment. But when other interests suddenly crop up, it upsets the whole thing. Somehow they don’t serve the purpose’. Previously, the GP was a very active user of the tools that DAMD provided:

For ten years, I have quietly looked after my business. I’ve been a good doctor, coded everything and all that, until I suddenly realized this ... this invasion of the professional authority or whatever you want to call it [...]. This was crucial for my involvement.

Firstly, it is important to note her experience of surprise when she suddenly realized that she provided data for many more purposes than what she thought she had signed up to do. It signals a new visibility of the infrastructure for the GP. This feeling of being surprised stayed with her: she likened it to a wide open backdoor to the consultation room, in which she had previously believed that confidential conversations took place. The developers of DAMD and the interviewed healthcare officials could not understand this perception. They emphasized that the GPs had agreed to have a technician come and install the software and had even

received a fee for it from the regional authorities. Therefore, they should have known. Nevertheless, while the GPs were aware that they were providing some data for the purpose of quality development, the expansion of the infrastructure and the exact travel routes of data had remained invisible to them.

When and how did the infrastructure then become visible to the GPs? When referring to an ‘invasion’ of her professional authority, the data-engaged GP referred to a particular political process: a process that started with the negotiation of the collective agreement for GPs in 2013 and developed into conflict, termination of the agreement and intervention by the national government. In this process, ‘data meant a lot’, a former director of DAK-E noted, explaining that the requirement of individual level performance data ‘led to fierce resistance among the physicians’. Whereas the regional authorities saw their requirement of data as a legitimate way to ensure efficient spending of public resources, a sizeable group of the GPs saw it as an unacceptable violation of their professional autonomy and patient privacy. Moreover, in line with the explanation of the DAK-E employees, the data-engaged GP expressed fears that expanded data access by health authorities would pave the way for data sale. It is unclear whether any concrete plans of data sale existed and whether they included DAMD data. However, the mere possibility of commercialization appears to have generated resistance. Following this value conflict, the data-engaged GPs started scrutinizing the flow of data from their computer systems in an effort to make themselves able to see the digital infrastructure they were part of. One of them recalled: ‘We found out that they not only had access to the projects we’d signed up for [...] They had access to the whole lot! This surprised us. This wasn’t what we’d imagined at all’. With ‘they’, the GP was referring to DAK-E. However, the GP soon realized she was part of an infrastructure with even more diffuse boundaries: she could not determine exactly who had access to which pieces of information, in which form and under which conditions. This experience of diffuse boundaries echoes a more general concern expressed in relation to the emerging data economy. As Pasquale (2015) notes: ‘Tracked ever more closely by firms and government, we have no clear idea of just how far much of this information can travel, how it is used, or its consequences’ (p. 3). Through conversations with IT providers, freedom of information requests, close reading of policy documents and other meticulous work, the digital infrastructure started to become visible to the data-engaged GPs.

Meanwhile, some of the GPs began having reactions from patients who had been pressured by insurance companies or municipal authorities to deliver printouts

of their medical records directly from the web portal Sundhed.dk, thereby sidestepping a doctor's certificate. Others saw how the availability of information at Sundhed.dk could escalate conflict or even lead to violence in some families, because partners or parents would share log-in information and have access to sensitive health data, e.g., about abortion or sexually transmitted diseases. It is unclear how widespread these situations were. However, the data-engaged GPs were dumbfounded by these scenarios. Akin to what has been observed in a British context (Carter et al., 2015), the data-engaged GPs publicly declared DAMD and Sentinel Datafangst a serious threat to patients' trust in GPs and a violation of privacy rights; broadcasted among others in YouTube-videos. So, the infrastructure that used to be seen as instrumental for good patient care was now made visible by these GPs to a broad public as a *threat* to patients.

Galvanized by what they discovered, the data-engaged GPs also started to dig into the legal basis for the data activities. As it turned out, this was rather unclear. Like in the Swedish LifeGene case described by Cool (2016), the infrastructure for data exchange had expanded in ways that did not fit the existing legal categories. According to the data-engaged GP introduced above, she and some of her colleagues sought to voice their concerns over what they saw as illegitimate and illegal data activity. However, they felt that they were not being heard – not even by their representatives in the GPs' own organization: 'No one could hear us!' the GP prompted. This fuelled an already existing power struggle among the GPs. Meanwhile, the national government had intervened in the conflict between the regional authorities and the GPs. Breaking with the tradition of consensus-based regulation through collective agreements, legislative measures were prepared that forced the GPs to report certain data to DAMD and made them subject to fines if they did not. As a consequence, the data-engaged GPs and others from the SPRAL network declared themselves prepared to terminate their contracts with the regional healthcare authorities and become truly independent from the public healthcare system. Moreover, two of the data-engaged GPs turned against their own representatives as they reported DAK-E and a regional government to the police for illegal data activity. The day before the new legislation was to enter into force, the same two GPs made it a Facebook-event when they and about 70 colleagues de-installed the Data Catch software, which allowed for automatic data extraction. Ironically, we may note, the use of Facebook to mobilize resistance meant that in order to defend privacy the GPs ended up using a commercial platform known for its voracious appetite for personal data. This seems to be the

situation in a data-intensive society, where nobody is able to know every aspect of the data sourcing in which they take part (Obar, 2015). The resistance of the GPs soon caught the attention of journalists. In the subsequent broadcasting of the case in national news media, the data extraction was repeatedly presented as illegal. In the course of the visibility created by the ensuing public debate, the focus of the parliamentary discussion began revolving around the legality of the data collection per se, and citizens started to demand that their data be deleted: about 20,000 citizens asked to opt out. In the autumn of 2014, a consensus seems to be reached among the national and regional healthcare authorities that the data extraction probably was illegal and the data sourcing was suspended. It took another three years before the GPs and the Regions reached an agreement that opened up for the sourcing of selected types of data for selected purposes starting in the autumn of 2017 (RLTN, 2017).

## Discussion and conclusion

For years, the challenge in digitalization of healthcare has been one of creating a 'digital fit' between users and technologies: a smooth and seamless work experience with a minimum of friction. In this paper, we have traced the rise and fall of a technology that had achieved just this goal. A group of dedicated GPs had created a promising infrastructure for data exchange; it provided easy and efficient data traffic and it was acknowledged for being helpful in the daily practice of GPs. The efforts of the developers to obtain seamless work experiences facilitated expansion of the infrastructure to encompass still more purposes; an expansion that remained largely invisible to the practicing GPs because it did not require additional work (cf. Berg and Goorman, 1999). Data multiplied, as copies were made and distributed to new actors and for new purposes. Hence, the seamlessness first created invisibility for those who produced the data (cf. Star and Ruhleder, 1996), which in turn created a 'spectacle' that overshadowed the practical evaluation of what the technology could and should do (cf. Larkin, 2013). Eventually, it caused the collapse of the DAMD infrastructure.

The added purposes reflected competing political projects. While first serving as a tool for doctors to monitor their patients, the political vectors gradually turned, and the data sourcing software grew into a potential tool for patients and authorities to monitor their doctors. STS scholars have already observed how digitalization of the medical record involved a transformation of the record itself from a clinical tool in the hands of the GP to an audit tool in the hands of authorities (e.g., Winthereik et al., 2007); simply

because data are available in an exchangeable format, the payers of the services can also demand data access. Our point is to consider how this transformation can lead to social conflict and in particular how the otherwise praised virtue of seamlessness plays a role in this process. Seamlessness made the expansion of data uses invisible, but did not erase the conflicting interests and political values. Seamlessness, in this way, has political implications but offers no political tools for handling potential conflicts.

As already mentioned, the Danish case is not unique. In England, *care.data* was met with opposition, when it became known that the database enabled reuse of data from electronic medical records from general practice for research and other purposes, including the aim of stimulating national economic growth (Carter et al., 2015). Also here, it was not a question of technical problems bringing data sourcing to a halt, but an inability to ensure political legitimacy (Vezyridis and Timmons, 2017). Garrety et al. (2014) have pointed out a tendency among decision-makers to focus on the technical capabilities of new IT systems, while overlooking the moral complexities of digitalized data sourcing. In an American context, investigative journalist Tanner (2017) calls attention to the invisible, seamless and ubiquitous data sourcing from pharmacies, laboratories and clinics, which bolsters commercial markets for health data, without providing the data sources – the patients – with any tools of control. These examples demonstrate how a seamless data exchange might have been a solution to the old problem of a poor fit between user and technology; but new dangers lurk in its aftermath, if we do not develop tools to negotiate the legitimacy of the emerging data infrastructures.

While we have pointed out cases of conflict, it is equally important to note that not all efforts to build up health-data infrastructures are troubled in this way (McCartney, 2014; Sethi and Laurie, 2013; Vezyridis and Timmons, 2016). For example, the Scottish Health Informatics Programme (SHIP) involved work to develop a new governance model, where ‘early and sustained stakeholder engagement was invaluable to identifying the key and diverse ethical, legal, social and practical issues implicated in delivering a more streamlined system’ (Sethi and Laurie, 2013: 180). This is not to say that the Scottish governance model will never encounter resistance or necessarily work elsewhere, but we think it points to a need for the development of political mechanisms suited for the local context, to ensure the social sustainability of data infrastructures. Discussion of the politics of social sustainability must also take into account knowledge about data validity. It is well-known that validity is affected by data reuse (Markus, 2001), and that healthcare professionals tend to report data strategically when they

are aware that data are being used for control purposes (Martin et al., 2013; Smith, 1995). To work in an educated way with political mechanisms must therefore also involve engagement with studies of the social mechanisms of data reuse and not be limited to legal contemplation of patient rights.

The paradox of seamlessness as a source of social instability has even greater relevance when we look beyond healthcare to the global data markets created by the big US high-tech companies, Microsoft, Google, Facebook, Apple and Amazon, as well as their Chinese counterparts Baidu, Alibaba and Tencent (Creemers, 2016). They thrive on seamless technology experiences. While providing for easy use, however, seamlessness also creates a blurred sense of control. As Obar (2015) notes, people are left with an obscure and insurmountable task, should they be held responsible for monitoring all data sourcing in which they engage in a digitalized society. When the ‘digital fit’ is finally achieved, new dangers lure in the shadows of the effortless interface. The problems of sustainability, that we forefront here, are of course not the only dangers that needs to be confronted considering the challenges to democracy, the role of media, national security and public trust that digitalized data accumulation also entail (e.g., O’Neil, 2016; Pasquale, 2015). However, we find the discussion of social sustainability a fruitful place to start as it raises questions of which mechanisms that may be needed to ensure that users are able to see the political work that is also being done by expanding digital infrastructures.

If seamlessness is not just an ideal of technical operability, but also a source of social instability, an important task for STS lies in supporting the establishment of new forums for the negotiation of conflicting values related to data sourcing. In efforts to enable data exchange, friction can be seen as the antithesis of seamlessness. Edwards (2010) speaks of ‘data friction’ as ‘the cost in time, energy, and attention required simply to collect, check, store, move, receive, and access data’ (p. 84). Friction creates a form of awareness of all the work going into data sourcing (cf. Berg and Goorman, 1999), but we are now at a stage where it takes other means to create this awareness. It is hardly a solution to reintroduce data friction and make the course of everyday work more difficult, just to raise awareness of data uses. Rather, we suggest that there is a new need to focus attention beyond the digital fit to political mechanisms for negotiation of values and interests to ensure the long-term sustainability of digital infrastructures. Along with the already massive investments in new technologies, we need to allocate resources to the development of political mechanisms to define and protect the rights and obligations of both data suppliers and users. We do not hold a solution, nor do we believe in a

master plan, but we find it necessary for new initiatives to be introduced aimed at investigating what it takes for digital infrastructures to be socially sustainable. First and foremost, it must be acknowledged that reuse of data comes at a cost, and that some purposes may conflict and eventually undermine an infrastructure. There are forms of reuse that are technically feasible but not worthwhile, considering the implications they have for primary purposes. Moreover, the easy click to agree to terms of use provided by most social media platforms does not perform well – it is part of the problem (Obar, 2015). Rather, a more socially sustainable digital development will necessitate development of legal frameworks at both national and international levels to protect data sources against data use working against their interests. This need for regulation has been acknowledged at the EU level. In August 2017, EU Commissioner of Competition Margrethe Vestager, who has gained fame for battling the dominance of the high-tech giants, called for a joint effort among international leaders to develop an International Data Convention (Fejerskov, 2017). It will take years of dedicated efforts to establish such an international convention (and it will undoubtedly create new problems). In the meantime there is work to be done in stipulating national legal entitlements in relation to, for example, transparency and limits to data uses (e.g., by limiting the market in data profiles used in recruitment, credit scoring, etc.), and in providing citizens with rights to rectify erroneous data profiles. Other options could be democratically elected or administratively appointed data guardians who can be held responsible for thinking through when and whether data reuse negatively affects the primary purposes of data collection.

None of these suggestions will in and by themselves create social sustainability, but we need to begin opening new political spaces in which a multiplicity of new tools may develop and conflicting values can be negotiated. The dangers of the digital fit involve a challenge to democratic governance, and we need to find ways to address this challenge without ruining the pleasures of a seamless user experience.

### Acknowledgements

We would like to thank Henriette Langstrup, members of POLICYAID research group, three anonymous reviewers, the editor, and the panel at the 2017 EGOS conference, where we first presented the paper, for generous comments on previous versions.

### Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This project has received funding from the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme (grant agreement number 682110).

### Notes

1. All translations from Danish to English have been made by the authors with assistance from professional proof reader Niels Coley.
2. To comply with the rules laid out in the Data Directive and honour agreements made with the informants to protect their confidentiality, we are unable to share the interview data that underpins the analysis. The documents, we build upon, are publicly available and copies can be sent upon request to the authors.
3. For reasons of confidentiality, the names mentioned in the analysis are all pseudonyms.

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